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YORK UNIVERSITY'S COMMUNITY NEWSPAPER

A cruel twist of Lyme

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Contributor



In the summer of 2008, York University student Anna Jaskolka visited Szczecinek, Poland, where she had lived until age two before coming with her family to Canada. It was a trip that would change her life dramatically, to a degree that has often made her feel suicidal.



(Pippin Lee)

The reason? A microscopic tick infected with the bacterium *Borrelia burgdorferi*, which causes Lyme disease, an illness few Canadians, including many medical doctors, know virtually anything about.

An avid runner at the time, Jaskolka went jogging in nearby woods, unaware that travelers to Poland are advised to be careful when in forested areas for fear of being bitten by an infected tick. “I always ran in my shorts and t-shirt,” she says, rather than the long clothing recommended for known Lyme areas. “I had never heard of Lyme disease.”

Soon after returning to Toronto, the normally happy and super-energetic political science undergrad

began to feel chronically tired and constantly in pain. Her body ached all over, especially her knees, a symptom common with Lyme victims. "I'm always in pain," the 24-year-old says. "It's like I have the worst flu every day."

A self-described "Type A" personality and life of the party, Jaskolka quickly became the complete opposite. "Two years ago in the summer I worked at a daycare from 7 am to 4 pm. Then at a retail job from 5 pm to 9 pm. And then at a bar until 3 am. I was never tired. Now I stay home all the time and all I do is play Nintendo with my boyfriend."

Jaskolka sought help from a slew of doctors, none of whom even mentioned Lyme disease.

Named after the small town of Old Lyme, Connecticut, where it was first discovered in 1975, the disease is well known in parts of the U.S., especially the north-east, but far less so in Canada. This will soon change, however, as birds migrating from the U.S. are transporting the ticks across the border and wetter, milder winters here are allowing them to survive and breed.

Many of Jaskolka's doctors prescribed blood work, but did not include a Lyme test. She was most often told she had fibromyalgia, a chronic pain disease that mirrors many of Lyme's symptoms. The medication she was given to treat the fibromyalgia made her more ill.

"My knees were so sore that I thought my shoes might be the problem, so I bought these old lady shoes, but they made no difference."

When nothing helped alleviate her pain and fatigue, some of the doctors, and also some family members and friends, suggested her problems were psychological, not physical. One doctor even went as far as to have her secretary tell Jaskolka never to come back to her office.

In the summer of 2009, Jaskolka's uncle, who is Polish, suggested she might have Lyme disease. "His mother had got it in Poland and he thought I might have it too," she says.

After conducting her own research Jaskolka felt her uncle was right. She asked several doctors to test her for Lyme, but they refused. Many Lyme sufferers experience that very same reaction when dealing with the medical community in Canada.

Even if a doctor does agree to a Lyme test, the one used in Canada, known as ELISA (enzyme-linked immunosorbent assay) has a reputation for producing many false negative results. Within the Lyme community (a small but very active group in North America), a second test, known as the Western Blot, is far more accurate. Few Canadian doctors, however, will order it if the ELISA is negative.

Jaskolka's health continued to suffer. So too did her social life. Many friends stopped hanging out with her. Many family members shunned her. She often felt frustrated by the consideration people give to cancer victims, a sympathy and understanding she has rarely been afforded.

"I've seen people go through cancer and it's so hard," she says. "But they get better in a few months to a year or they die. Either option is better than what I am going through." Sometimes, she admits, she has felt so despondent that suicide has crossed her mind, although she's sure she would never actually go that far. After she read an article I wrote on Lyme for the Toronto Star last July, Jaskolka contacted someone I had interviewed. He told her to send her blood to a private lab in the U.S., at her own expense, to have a Western Blot test conducted. It came back positive for Lyme disease.

She was eventually able to find a local doctor willing to treat her for Lyme. He is one of the few physicians in Canada willing to prescribe the long-term and massive doses of antibiotics that are the

primary treatment for someone who was not diagnosed within about 48 hours of being bitten; in those cases antibiotics can usually remove the infection from the body.

An indication of how paranoid doctors tend to be about Lyme, which some medical experts believe is not an actual disease, Jaskolka's doctor didn't want to be named for this article. Another Toronto- area doctor who treated Lyme victims recently retired after being harassed by the medical governing bodies because of his practice.

Now under treatment designed to combat Lyme disease, Jaskolka is feeling a little better. Her doctor says she might be better in a year and a half from now. She had to drop some courses last year because of her fatigue and is finishing her fourth year on a reduced workload. She has a note from the disability office that says her condition has to be factored in by her professors. One of them, she feels, didn't believe she had a real problem.

Her new doctor has given Jaskolka hope for the future, but at present she speaks of what lies ahead with a certain sad resignation. "I'll graduate this year, but what will I do then? I can't commit to a full-time job. What do I have to talk to others about? They are looking forward to their lives and accomplishing things, but I'm kind of standing still."

One hope she does have is that people would be more understanding about what she is going through. "I wish people would take [Lyme disease] more seriously," she says. "I feel like I can't talk to anyone because they don't know what I'm going through." She smiles as she says that, but her eyes are sad and full of pain.

Lyme Disease

Nasty bugs

The Canadian tick population is found most commonly in southern and eastern Ontario, but spans four out of five regions.

Symptoms

The first noticeable symptom of Lyme disease is a rash on the body. Other symptoms include fevers, headaches, blurriness and neck stiffness.

History

Lyme disease was first discovered in 1975 in the United States in a small town called Old Lyme, Connecticut.

Protesting patients

In 2007, 100 Lyme disease sufferers headed to Parliament Hill to protest on behalf of better Lyme disease testing and increased federal funding for research.

Nationally underreported

In Canada, Lyme disease is still not a nationally reported disease.

Presidential problem

In 2006, then-U.S. president George W. Bush was treated for Lyme disease.

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